

**Carol Tyndall Conlon interview, 2014-12-16 : interview conducted by Michael
Robert Bussel**

INTERVIEW LOG

00:00:22: Other jobs before becoming caregiver for her son: medical transcriptionist, worked for lawyers, Oregon Health Plan, managed office for Habitats for Humanity. Moved to Oregon in 1981.

00:02:21: Formal care for her son when he “aged out” of high school. Has been his caregiver since 2001. Long waiting list for group homes. Son needed more emotional support and nurturing. Has autism, “child in adult’s body.”

00:04:57: More one-one-one time with her son and greater bond developed. Increase in his confidence and abilities. Outcome of his growing independence will determine what type of care is subsequently needed.

00:07:48: Left private sector employment to focus on her son. Learned more about him by having time to observe. Example: son disturbed while she was driving. Expressed empathy. Son is now more expressive. Signals that he wants to be touched, looks her in the eye more often. “Accidental breakthrough,” unexpected benefit.

00:11:24: Patience key in working with people with disabilities, especially those with cognitive disabilities. Lots of frustration when you can’t do things. Must not show frustration as a caregiver. Do job to best of your ability. Employment is a journey.

00:14:51: Finding other caregivers important in dealing with autism. Autism support group, people share tips on what works—immensely helpful. Sense of camaraderie and not being alone. Immediate bond.

00:17:45: Receives calls from families around the state. People say “you understand me.” In previous job, asked to speak with parents of children with developmental disabilities. They say, “Now I trust you” once they learned she had child with autism.

00:21:17: Common denominator: finding someone who understands, who will believe you and trust you.

00:22:39: Families of children with disabilities experience discrimination. Insensitive comments from others. Discrimination against her son because of his lack of cognition. Unique experience of being family caregiver does not go away once children become adults. Sense of protectiveness and desire that children have opportunities to access needed services.

00:24:15: Caregivers as parent. Have to advocate for their children, be their voice. Protect their health, safety, welfare, rights.

00:26:28: Typical day. Cues her son the night before to get ready for work the next day. Quiets house, lowers lights. In morning, opens door, turns on light, announces time they will leave. Prepares breakfast, lunch, snack he will like. Talks about appropriate clothing. Sets the mood. Relationship building.

00:30:14: Brings her son home from work. Asks about his work day. Cues with specific times for things to get done. Will be important when he begins to live more independently.

00:31:42: Electronic devices help her son. Check in verbally, visually by text. At fast food restaurant when son is ordering, only steps in as needed. Has seen positive effects on people who interact with her son.

00:34:02: In coffee shop, people love her son. Know his idiosyncrasies. He has developed friendships. Quality of life better for her son. Now laughs, has sense of humor. Pulled him out of his shell. Different person emerging.

00:37:13: Humor is part of bringing her son into experience of human relationships. Son has learned to laugh at himself. Importance of inclusion in schools for disabled kids.

00:39:20: Empowering for those with disabilities to have experiences similar to those who are non-disabled. Build self-confidence and independence. Define success on basis of overcoming challenges. Son got a standing ovation from audience when he graduated from high school. Profound moment. Fellow students changed by contact with her son.

00:45:03: Approached SEIU seeking help on policy advocacy. Labor issues and advocacy intertwine, overlap. Union actually listened. Felt validated. Union has helped on political side.

00:47:46: Called to testify before legislative committee. Noted deficiencies in policies and their effects on people with disabilities. Able to get significant legislation passed. Changes mean “my son is going to have a life.”

00:51:20: Job is ongoing. Has safety net in place when she is not around. Need complete break at times. Wants others involved as part of her son's transitioning.

00:53:51: At a crossroads. Didn't want to place her son in setting with people who might not understand his needs. Had to make a choice. Sacrifice so her son could be the best and most independent person he could be. Who best to help him transition but someone who is most familiar with him and could be his advocate. Family caregivers will not outlive their children. Need to make a gradual transition.

00:55:52: Digital scrapbooking as a leisure time activity.

00:57:35: Early years, only knew one other mother who had child with disabilities. Felt like two lone people. Got to be more of us. Learned if something is not right, don't dismiss it. Never dreamed we would have another group in union to add to home care. Blind faith, had no navigational tools. Now get training, paid health care, camaraderie, community. What if people had given up?

01:00:27: New policies. My child will have a life. Things we do in life that don't have a title or earn economic compensation. Gratifying. Pushed against fears. No road map. Inner satisfaction. Improve workers' lives and quality of life for clients.

01:02:19: End of interview.